# **NC Brain Injury Advisory Council**

North Carolina acknowledged Traumatic Brain Injury (TBI) as a disability category 30 years ago and we still do not have earmarked funding to support services for this growing group.

The Centers for Disease Control (CDC) indicate 1.7 million TBI's occur each year in the United States and results in 52,000 deaths, 275,000 hospitalizations, and 1.3 million emergency department visits. Based on the projected population for North Carolina of 9,752,073 we can estimate 195,041 people sustained a brain injury in 2013. As our population grows so will the number of people living with a brain injury.

Currently access to services for adults is limited and must be improved before our inadequate and already overwhelmed systems feels the full effect of untold numbers of veterans returning from Iraq and Afghanistan with traumatic brain injuries. We can no longer ignore that brain injury can result in behavioral problems, along with the physical and cognitive challenges – changing a person's relationship with family, friends and community. In many cases appropriate services are scarce, or are simply nonexistent in most areas of North Carolina. Statewide there are only 58 TBI specific beds for people with brain injury. Some other beds are privately owned and not reimbursed by Medicaid or most private insurances. The homeless on the street and those in prisons include many people living with a brain injury where even access to an institution was denied. It is time to recognize that providing accessible, and beneficial services is a cost effective investment for our state.

As we struggle with ways to increase our economy and reduce our state budget it is even more important to look at the benefits of increasing funding for those who have survived traumatic brain injury. The value of intervention following a brain injury must start immediately in order for the person to reach their maximum potential. Being shortsighted will ultimately cost our state more in the long term, such as the high cost of caring for a survivor who could be more independent if a few dollars had been spent early on, the loss of productivity for someone who can reach full recovery with immediate intervention.

TBI is truly a great equalizer: The perception it only happens to those who are being reckless is simply not accurate; it can and does happen to OUR friend, family member, father, mother; as the result of a fall, vehicle accident, spousal abuse, riding a bike, or a boulder being tossed from a highway overpass.

We trust the following information will help the legislature to develop an action plan that will provide appropriate funding and treatment for persons living with brain injuries.

# **TBI DEFINITION & STATISTICS**

#### • THE STATUTORY DEFINITION OF TRAUMATIC BRAIN INJURY IN NC FIRST APPEARED IN 1985

Traumatic Brain Injury is defined in NC Statute within the definition of Developmental Disabilities in *Chapter 122C of the Mental Health, Developmental Disabilities, and Substance Abuse Act of 1985* as follows:

#### 122C-3. Definitions

(12a) "Developmental disability" means a severe, chronic disability of a person which:

a. Is attributable to a mental or physical impairment or combination of mental or physical impairments;

- b. Is manifested before the person attains age 22, unless the disability is caused by a traumatic head injury and is manifested after age 22;
- c. Is likely to continue indefinitely
- d. Results in substantial functional limitations in three or more of the following areas of major life activity: self-care, receptive and expressive language, capacity for independent living, learning, mobility, self-direction and economic self-sufficiency; and
- e. Reflects the person's need for a combination and sequence of special interdisciplinary, or generic care, treatment, or other services which are of a lifelong or extended duration and are individually planned and coordinated; or"

# • DDHS DEFINES TRAUMATIC BRAIN INJURY AS AN INJURY CAUSED BY A BLOW TO THE HEAD RESULTING IN BOTH PHYSICAL AND MENTAL LIMITATIONS

- Services are provided for:
  - People with TBI who also meet qualifications for the MH/DD/SAS for Developmental Disabilities
  - People with mental illness and/or substance abuse who also have a traumatic brain injury
- o It is unclear who decides the level, kind, and funding of services afforded those who meet the DD criteria but whose injury occurred above the age of 22

#### Number of people who have survived a traumatic brain injury in NC – children and adults.

Data on TBI is not tracked in a systematic way but one method of estimating potential numbers is to look at the number of persons with TBI discharged from the hospital or seen in emergency departments. While this does not capture those who were seen outside of those arenas, it provides insight into the demographics of this population by age and frequency on an annual basis. From these statistics we know the following:

- o The number of persons with TBI discharged from hospitals is increasing
- o The number of fatalities of those hospitalized with TBI is decreasing.
- The number of TBI survivors visiting Emergency Departments is increasing.
- o The number of fatalities of TBI Emergency Department visits is decreasing.
- $\circ\quad$  The number of males discharged from the hospital is greater than females with TBI
- o Children between ages 0 4 have high rates of hospitalization and even higher rates of ED visits for TBI
- Adults over age 84 have the highest rates of TBI deaths, hospitalizations and ED visits (5228) for 2011-2012
- o TBI hospital discharges for TBI survivors ages 20-64 totaled 3240 (c. 44.5%) out of 7,276 (2011-2012)
- TBI emergency room discharges for survivors ages 20-64 totaled 32,502 (43.9%) out of 73,996 (2011-2012)

North Carolinians are almost 4 times more likely to be hospitalized and nearly 40 times more likely to visit an Emergency Department than to die from a TBI.

Table 2: Gender and Age, Hospital Discharges, and Emergency Department (ED) Visits due to TBI: North Carolina Residents, 2011 and 2012. The following data is taken /adapted from (The Burden of Traumatic Brain Injury in North Carolina in NC, March 2014)

Gender	Hospital Discharge (2011)	Emergency Room Visits (2012)
Male	4,321	38,392
Female	2,955	35,589
Age Group		
0-4	313	8,861
5-9	115	4,641
10-14	120	5,055
15-19	400	6,950

TOTAL	7,276	74,228
85+	978	5,228
75-84	1,220	5,888
65-74	890	4,869
55-64	794	5,149
45-54	799	6,470
35-44	554	6,365
25-34	634	8,283
20-24	459	6,235

Studies have shown that each year approximately 20% of the c. 6,000 + North Carolinians hospitalized for TBI can be expected to require extensive rehabilitative services

# The Numbers Are Growing

TBI Hospitalizations 2008-2011					
	2008 N(%)	2009 N(%)	2010 N(%)	2011 N(%)	
TBI Hospitalizations-Survivors	6,380 (91.1%)	6,417 (91.7%)	6,748 (92.3%)	6,714 (92.3%)	
TBI Hospitalizations-Fatalities	621 (8.9%)	579 (8.3%)	565 (7.7%)	562 (7.7%)	
Total TBI Hospitalizations	7,001	6,996	7,313	7,276	

TBI Emergency Department Visits 2008-2012					
	2008 N(%)	2009 N(%)	2010 N(%)	2011 N(%)	2012 N(%)
TBI ED Visits-Survivors	51,102 (99.7%)	59,007 (99.7%)	62,021 (99.7%)	68,604 (99.8%)	74,053 (99.7%)
TBI ED Visits-Fatalities	157 (0.3%)	150 (0.3%)	159 (0.3%)	136 (0.2%)	175 (0.3%)
Total ED Visits	51,259	59,157	62,180	68,740	74,228

# **CURRENT SERVICES**

# WAIVER SERVICES

- o The Innovations 1915(c) Waiver serves only those TBI survivors whose injury occurred prior to age 22.
- The 1915 (b) Waiver is designed for Mental Health or Substance Abuse; a TBI survivor can only be served if they
  first have a mental illness or substance abuse diagnosis.
- The CAP-DA (Disabled Adult) Waiver is designed to provide an alternative to institutionalization for people who prefer to remain in their primary residence and would be at risk for institutionalization without these services. The service menu is not designed or funded for TBI and is not broad enough to incorporate all the service needs of persons with brain injury.

# No North Carolina Medicaid Services or current Waiver Services includes TBI specific service definitions, licensing requirements, or appropriate reimbursement rates.

#### OTHER STATE AND COUNTY FUNDS

Medicaid State Plan services were developed for MH, DD and SA disabilities. Services include mobile crisis, outpatient therapy, diagnostic assessment, personal care, developmental therapies, residential supports, and respite but are not designed for brain injury. While these services may be helpful for many who qualify for Medicaid, they are not specifically designed for brain injury.

#### \*\*LME-MCO ESTIMATES OF TBI SERVICES (2012-2013) – March 24, 2014

- LME/MCOs report serving under the Innovations Waiver, 16 children and 96 Adults whose injury occurred before the age of 22
- LME/MCPs report serving 45 children and 423 adults using savings and state dollars combined (unsure as to whether the injury occurred before or after the age of 22)
- These numbers are only estimates since this information has never been requested or collected routinely. The numbers more than likely represent underestimates in some cases and combine different categories and sources of funding from one LME-MCO to the next.
- \* THE CONTINUING STATE APPROPRIATION FOR TBI appears in the annual DMH budget. \*This amount is determined each year at the discretion of the Division of MH/DD/SAS and is in no way guaranteed. The purpose of these funds is to serve as "funding of last resort" for specialized brain injury residential services and day programs for the following:
  - Those not eligible for the waivers including those injured after age 22
  - Those who are not Medicaid eligible
  - To provide some start-up funding for new service models

State Fiscal Year	TBI Money Requested	Total TBI Money Available	Shortage
2010	\$3,105,047	\$2,344,862	\$760,185
2011	\$4,056,185	\$2,384,863	\$1,671,322
2012	\$3,259,888	\$2,393,086	\$1,226,020
2013	\$3,530,202	\$2,393,086	\$1,137,116
2014	\$4,110,311	\$2,353,034	\$1,757,277

- o In FY 2013, TBI money served 152 individuals at an average of \$15,743.
- 48% sustained their injury after age 22
- 51% were living in group homes with assistance from these funds
- The average age served was 40
- o 92% were between ages 18-58
- 58% sustained their TBI between ages 16 35
- o 91% were unemployed
- o 90% report income less than \$25,000
- 53% used TBI funds for housing
- o 60% were sustained in moving vehicle crashes
- Limited Non Profit Project for Veterans who participate in the Hind's Feet Farm Clubhouse programs are funded through a time limited grant from Wells Fargo and some Veterans receive case management and home based care through a program funded by the private non-profit Wounded Warriors project.

O <u>Division of Vocational Rehabilitation</u>: The Division of Vocational Rehabilitation (VR) is an agency within the DHHS that is 80% federally funded and matched with 20% state funds. VR serves on an annual basis approximately 1,100 individuals with TBI and other neurological/cognitive disabilities in providing job training, job development, job supports, and other services that aide in the pursuit of competitive employment. This population typically requires a high level of supports to maintain competitive employment referred to as extended follow-along services. The success of these individuals with long-term employment stability after vocational rehabilitation services are completed is often heavily dependent upon limited funding sources within the current mental health system to meet this need, which may or may not be available within their community, thus jeopardizing their jobs.

# Specialized Services for TBI available across the state – rehabilitation, residential, at-home, acute care

SPECIALIZED TBI PROGRAMS IN NORTH CAROLINA 2014			
Program Type	Program Name	Location	Capacity
	Hinds Feet Farm	Asheville	13
Clubbouse (2)	Hinds Feet Farm	Huntersville	17
Clubhouse (3)	Gateway Clubhouse	Raleigh	14
		TOTAL	44
	ReNu Life Extended	Goldsboro	24
	Taylor Home	Goldsboro	6
	Pineview Home	Goldsboro	5
	Lakeview	Goldsboro	6
	Lippard Lodge	Clemmons	6
Residential (8)	Person County Group Homes Inc., TBI Program # 2-3	Leasburg	4
	Gaston Residential Services, Inc.	Gastonia	4
	VOCA-Elm	Hudson	3
		TOTAL	58

# **KNOWN SERVICE GAPS:**

#### NORTH CAROLINA'S VETERANS AND THEIR FAMILIES WILL NEED SUPPORT AT HOME

- AN ESTIMATED 19.5% OR 24,429 RETURNING NC VETERANS WILL EXPERIENCE ONE OR MORE TRAUMATIC
   BRAIN INJURIES. These veterans and their families will need assistance in their home communities
- The Veteran's Administration (VA) provides services for the large number of military service members in NC who have sustained a TBI in the course of their military duties.
- There is no specific directory of covered services for individuals with TBI but each military branch has its own set of requirements and standards for disability eligibility which difficult for veterans and their families to navigate.
- Family members are not covered for their secondary psychological stress issues.
- o In 2009-2010, it was estimated that 54,000 veterans and 43,000 family members were uninsured.

### NC DOES NOT HAVE A COMPREHENSIVE CONTINUUM OF NEUROBEHAVIORAL SERVICES

The most persistent needs over the lifetime of a person with brain injury are help with cognitive changes (difficulties with attention, memory, judgment and reasoning) and assistance with behavioral challenges (impulsivity, agitation and a variety of emotions) and the impact of these issues on their ability to function daily. Many individuals also require personal care/assistance to remain in their communities. A statewide needs assessment conducted by The Clinical Center for the Study of Development and Learning in 2008\* identified the following unmet needs for brain injury neurobehavioral services:

- A neurobehavioral continuum of rehabilitative, residential services /day programs
- o Crisis assessment, intervention, management and mental health support including a hotline

- Supports for service access and coordination (information and referral a resource team)
- o Family education, support and respite (including home health care and help) needed "everything"
- Housing and transportation
- o Training in TBI needs and management for HHS personnel, LME-MCOs, medical and other service providers including caregivers

Despite a significant increase in fiscal year 2008 for the TBI program under the Division to \$2.3 million, the TBI program remains underfunded and statewide community capacity is minimal.

# NC LACKS TBI APPROPRIATE RESIDENTIAL, REHABILITATIVE (Acute & Long-term) and AT HOME SUPPORTS

- Lack of sufficient availability of a residential and day programs knowledgeable about TBI management
- Lack of TBI service definitions to reflect the unique rehabilitative and long term needs of survivors
- Lack of individualization of TBI residential and home support services including personal care
- o Lack of appropriate reimbursement rates to reflect the higher cost of caring for TBI survivors

#### THE ACTUAL NUMBER OF UNSERVED CHILDREN AND ADULTS IS NOT AVAILABLE

- o It is impossible to provide projected numbers for the unserved children and adults because we do not have a tracking system in place in the State of North Carolina to record and follow TBI survivors.
- One LME-MCO identified "23 ... consumers that had TBI diagnoses but had no services between 7/1/2012 to the present."

With targeted intervention, even the more severe TBI survivors could, at a minimum, require less costly supportive care and others could achieve full community integration and employment

#### **HOW OTHER STATES HAVE ADDRESSED THESE NEEDS**

# • TWENTY-TWO (22) STATES HAVE TBI WAIVERS

- Section 1915(c) of the Social Security Act allows States to provide an array Medicaid funded home and communitybased services (HCBS) that are in addition to State Plan services to targeted populations or targeted areas of the State for defined groups of individuals who are Medicaid eligible and are at risk for institutional or nursing facility services.
- Since 1991, almost half of the States have implemented HCBS Waiver programs specifically for TBI. States also provide HCBS waiver services to individuals with TBI through other waiver programs, such as waiver programs for physical disabilities or intellectual/ developmental disabilities. Services covered consist of case management, therapies, in-home supports, personal care, durable medical equipment and in-home modifications.
- At least 22 states and the District of Columbia currently operate a Medicaid Home-and-Community-Based Services (HCBS) waiver targeting persons with TBI.

An Overview of Brain injury Waiver Programs by State and Services Offered
FY 2011 1915c TBI Medicaid Waiver Expenditures

<sup>\*</sup>Traumatic Brain Injury in North Carolina: Preliminary Needs Assessment, Clinical Center for the Study of Development and Learning, UNC at Chapel Hill in collaboration with NC Division of MH/DD/SAS, March 28, 2008

FY 2011 1915C TBI Medicaid Waiver Expenditures

	STATE	EXPENDITURE
1	Colorado	\$12,899,327
2	Connecticut	\$38,623,676
3	Delaware	\$ 1,346,065
4	Florida	\$10,144,866
5	Illinois	\$84,854,617
6	Indiana	\$4,479,068
7	Iowa	\$22,524,528
8	Kansas	\$13,794,932
9	Kentucky	\$16,816,505
10	Maryland	\$4,771,807
11	Massachusetts (3)	\$7,944,878
12	Minnesota	\$92,892,461
13	Mississippi (TBI/SP)	\$18,142,825
14	Nebraska	\$660,505
15	New Hampshire	\$16,096,094
16	New Jersey	\$24,993,236
17	New York	\$117,949,513
18	Pennsylvania	\$48,439,910
19	South Carolina (TBI/SP)	\$21,770,172
20	Utah	\$2,739,318
21	Wisconsin	\$6,621,211
22	Wyoming	\$6,974,406

# MEDICAID EXPENDITURES FOR SECTION 1915(c) WAIVER PROGRAMS IN FY 2011 – October 2013 (CM

#### TWENTY-THREE (23) STATES HAVE TBI TRUST FUNDS

- o Twenty-three (23) States have enacted legislation designating funding
- These "trust funds" are largely comprised of resources from traffic fines and/or surcharges to vehicle registration and motor vehicle licenses.
- The revenue is usually collected by county clerks and forwarded to the State treasurer to be placed in a non-reverting account. The legislation designates a State agency to administer the funds. Most States have established an advisory body to provide input and oversee the fund. There is variability across the States with regard to the amount generated and how the funds are used.
- Estimated revenues are from less than \$1 million to \$22 million with an average between \$1 million and \$4 million annually.

A LOOK AT TBI TRUST FUND PROGRAMS; Possible Funding Sources for Helping Individuals and Their Families Cope with Traumatic Brain Injury Updated, January 2012

# THE DEFINITION OF TBI HAS BEEN EXPANDED IN AT LEAST EIGHT (8) STATES

A number of states have expanded/changed their definition of TBI to include ABI as well as their service capacity either as a result of evolving recognition of need or following Olmstead decisions or civil litigation. The waivers in Massachusetts define Acquired Brain Injury as "all forms of brain injury that occur after the age of 22 which are not due to Alzheimer's Disease or other similar neurodegenerative diseases with a primary manifestation of dementia." At least 8 states have similarly expanded their definition of traumatic brain injury but vary as to the breadth of their inclusivity."

# STATE TBI PROGRAMS

**Note:** Many States, including North Dakota and Alaska, receive State appropriated funding for specific TBI services, such as service coordination. Also, Michigan is in the process of submitting a Medicaid HCBS waiver.



Map Key:

**Trust Fund Programs (Yellow)** 

TBI Medicaid HCBS Waiver Programs (Red)

Both Trust Fund and Waiver Programs (Green).

Combined their TBI Waiver programs into other HCBS or long-term care waiver programs (Blue)

Provided by NASHIA (National Association of State Head Injury Administrators)

### WHY IT IS CRITICAL TO ADDRESS THESE NEEDS NOW

#### Legislative progress to date

The Division of Mental health was charged in 1985\* with responsibility for populations other than mental retardation, including traumatic brain injury (TBI) regardless of age on onset. First appropriations for TBI occurred in 1993-1994 (\$300,000 & \$225,000). In 1996, the Governor designated DMH as the Lead Agency for TBI following the federal TBI Act of that year and NC received the first 3 year federal HRSA grant of \$200,000 with \$100,000 in state match; subsequent 3 year grants were obtained in 2006 and 2009; an application was submitted last week for a fourth HRSA TBI grant. A DMH funding appropriation in 1999 for an in-patient neurobehavioral unit was diverted after Hurricane Floyd. In 2001, DMH set aside \$400,000 due to Coalition 2001 efforts for the development of a TBI Waiver; the money was instead used as "funding of last resort" for persons with TBI and supplemented by \$ 1million from the Mental Health Trust Fund for community-based services for TBI for a total of \$1.5 million; (this fund totaled \$2.3 million in 2013; (requests in past years have been as much as \$4 million). Efforts to obtain a funding match for a TBI Waiver occurred again in 2009 and 2011 without success. The Brain Injury Advisory Council was established in 2003. In 2009, HB 1309 directed MH/DD/SAS to adopt TBI specific rules providing for the licensure and accreditation of residential treatment facilities that provide services to persons with TBI in addition to the direction for developing rules relative to the TBI Waiver but without the allocation of matching funding neither proposal was implemented.

Next year it will be 30 years since TBI was first legislatively recognized in North Carolina.

# PERSONS WITH TBI HAVE BEEN UNDERSERVED FOR YEARS

- o The lack of specific inclusion in any NC waivers or Medicaid
- Disparity of service delivery between those injured before age 22 and those injured after age 22
- There is a persistent insufficiency of funding and no guaranteed amount for the TBI monies "of last resort"
- Specialized TBI appropriate community based services are lacking in availability and accessibility
- Inadequate information for families and survivors on availability and location of services
- o The absence adequate numbers of TBI specific transitional and long term care facilities along a continuum
- O The lack of a point of leadership for the delivery of TBI services, interagency coordination and collaboration
- Inadequate TBI awareness and expertise within agencies and among service providers
- O The continuing lack of support services for overwhelmed families and struggling survivors

# • THE POPULATION IS GROWING

It is estimated that roughly 2%\*of the population or 195,041 North Carolinians live with a mild, moderate, or severe traumatic brain Injury\*\* which can result in lifelong impairment requiring long term supports.

\*\*Based on 2% of the 2013 population estimate

The following population projections are based on the historical trends of the state and expected migration, birth, and death rates and the estimated projection that 2% of the population live with a TBI.

Year	% Increase from 2010 census	Population	2% TBI
2013	2.3%	9,752,073	195,041
2015	3.4%	10,088,000	201,760
2020	9%	10,629,000	212,580
2025	14.6 %	11,171,000	223,420
2030	20%	11,712,000	234,240
2033	23.4%	12,036,000	240,720

http://www.osbm.state.nc.us/ncosbm/facts and figures/socioeconomic data/population estimates/demog/Countyto

# • THE IMPACT ON FAMILIES AND THE ECONOMY IS GROWING

The majority of services currently available in NC for persons with TBI are designed for persons with developmental disabilities and do not reflect the unique medical, physical, cognitive and behavioral needs of this population. Without TBI specific service definitions, licensing requirements and appropriate reimbursement rates, no comprehensive state-wide system of services exists.

#### The consequences are:

- o Some are not being released from hospitals for lack of available and appropriate options.
- Many others find themselves served in inappropriate and higher cost settings such as state mental hospitals and nursing homes.
- Those who do not receive appropriate services are at higher risk for drug addiction or incarceration.
- Many who return from the hospital or rehabilitation facility find no bridging services to facilitate continued recovery. Some family members liken returning to their home communities as "like falling off a cliff".
- New research is showing that without appropriate intervention many decline both medically and behaviorally and ultimately require far more costly interventions and residential services.

Nearly all TBI survivors will fail to receive the rehab they require to reach their maximum recovery potential, because of this society ends up paying in three ways:

- 1. A higher cost care because money was not spent to obtain the best outcome immediately following the injury, and now we have a more involved long term care cost.
- 2. The loss of potential productivity because a TBI survivor is not rehabilitated to their full potential.

Our system fails the survivor and the financial burden falls on the family and ultimately on society.

### Potential for class action lawsuit

States responding to legal findings include Colorado, New York, Georgia, Connecticut and Massachusetts. A class action suit in Massachusetts (*Hutchinson v Patrick*)\* sought to enforce the rights of brain injury survivors by ensuring access to community-based living, and freedom from discrimination and segregation in the provision of long term care as guaranteed by the Americans for Disabilities Act (ADA). This past June, approval was granted by a US District Court judge for an Amended Settlement Agreement in the longstanding class action lawsuit, offering nearly 1200 people with brain injury in the state of Massachusetts the opportunity to move out of nursing homes and into the community.

http://www.centerforpublicrep.org/litigation-and-major-cases/brain-injury/the-litigation-hutchinson-v-patrick http://www.mass.gov/eohhs/docs/eohhs/braininjury/110606-amy-bernstein-deb-kamen.ppt

#### RECOMMENDATIONS PRIORITIZED:

# TBI Medicaid Waiver – to be managed by LME/MCOs

A HCBS/TBI waiver to be administered by the Department of Health and Human Services and managed through the LME/MCO's to assure access to TBI services in communities throughout the State.

The waiver would use Medicaid funding to provide supports and services to assist individuals with a traumatic brain injury (TBI) toward successful inclusion into the community. The waiver services would include those between the ages of 22 through 64 with an array of TBI specific supports from which to choose. The services would include community based supports that would allow people to live in the least restrictive environment and to be engaged in productive daily activities.

#### Increase amount of continuing state appropriations – and legislative mandate

This money needs to be increased, and legislatively mandated so adults who do not qualify for Medicaid, due to the fact even small SDI incomes are too high for individuals to qualify and too little to pay for needed services. This money in many cases is a resource of last resort, which makes it imperative that it remain available and consistent for adults who need assistance but cannot qualify for Medicaid. Funds are also needed to support a full-time Program Coordinator, knowledgeable about TBI, in the Division of MH/DD/SAS.

# Study Commission to investigate structural and operational issues, data collection, service and service access gaps, needs.

A Study Commission is needed to determine the service needs of individuals with Traumatic Brain Injury (TBI); improve capacity to identify injured persons in order to facilitate and coordinate their rehabilitation and other needed services; to gather data for injury prevention and control; to gather data for health care planning; and to evaluate services provided to TBI injured persons.

We cannot adequately respond to the needs of people with brain injuries without a way to determine the number and characteristics of people affected by TBI. Regardless of the approach, advocates, policy makers, and TBI service providers agree that TBI data must be specific to effectively inform primary prevention activities, policy development, and planning to ensure adequate services for people with TBI.